

Family, faith and a sense of humour help Cindy cope with Parkinson's Disease

by Parkinson Canada

"You should have seen me back then. I'd be sitting on the tailgate of the station wagon with the youngest on my lap. My middle son would be tearing around on his tricycle and we'd be watching my eldest boy play baseball; cheering him on," remembers Cindy Smith as she looks back on her days as the mother of three young sons, with her husband Tim away with the navy. That was just before learning she had Parkinson's disease, at 35 years of age.

In 1996, she'd gone to her family doctor about a jiggling finger on her left hand. She thought maybe she had a wonky muscle or tendon. She was surprised when her doctor referred her to a neurologist. The specialist said he knew by the way she walked into his office, with limited arm movement, that she had Parkinson's disease. There is no simple blood test or other diagnostic tool to confirm a diagnosis. They did several tests, including an MRI, to rule out other possibilities.

"I was taken aback," says Cindy. "I didn't know much about Parkinson's, except that it was something old people got."

For the first year or two, Cindy didn't take any medication and carried on as a busy Mom with a husband in the navy. She didn't have too many symptoms at the time that affected her lifestyle. Eventually, she started taking levodopa and within four years, the family moved from Dartmouth to Hilden, close to Cindy's family and Tim got a job on land. "We knew that eventually I was going to need more help."

Aside from close family and friends, Cindy did not announce her disease to others and she didn't have to deal with telling an employer. She and her husband didn't tell the children when they were young and the children didn't ask any questions in the early years. "It was a busy time," says Cindy. "There were beavers, cubs and scouts; sports and school. We did it all. Everybody pitched in and Tim was no longer at sea."

Cindy did go to a Parkinson's support group – once. She was by far the youngest person there and most of the participants were using walkers or wheelchairs and Cindy just found it frightening and depressing. (Writer's note: Today, there are Parkinson Canada support groups especially for people with Young-onset Parkinson's disease (YOPD))

By the time Cindy was 50, and in her second decade living with the disease, she was finding it much more difficult to cope. She was taking pills every two hours to deal with her symptoms. "I'd have very short windows of time to do anything. I could take a shower, or hang some clothes on the line, or peel the potatoes. I would start something and then I'd have to get someone else to finish it. Some nights, I'd have to wake Tim to help me move in bed to get comfortable. I couldn't move on my own."

Eventually, Cindy was put on the list for a procedure called deep brain stimulation (DBS) surgery. It is brain surgery that is performed while the patient is awake; placing electrodes precisely within the brain. The stimulator device is implanted in the chest (like a pacemaker) and a battery pack is worn outside the body.

Cindy underwent two procedures in the spring of 2012, one for her left side, and three weeks later a second procedure to address the right side of her body. "My head was shaved and painted orange from the disinfectant," says Cindy. "I was quite a sight. The neurosurgeon had a sense of humour and after he opened my skull, I remember him saying: 'Well, Cindy, this is a good looking brain you've got here.'" Cindy continued to joke with him through the operation. "I had to keep saying my name and my address, while he was working. Sometimes I'd say a different name, or address, just to lighten things up."

Once the stimulation device was calibrated, Cindy had to gradually wean herself off her medications, with her doctor monitoring, before the full effects of the DBS kicked in. "It was totally worth the risk. I had very few symptoms and took no medication for a few years." Unfortunately, DBS does not stop the progression of the disease. Cindy now takes some medication and is dealing with other health issues, but still she feels better than before the DBS.

Cindy credits her sense of humour, the support of her family and her church family with her ability to cope with this complex disease. She does worry about the future, especially the possibility of dementia, which is a common symptom of Parkinson's, especially in its later stages.

In the meantime, she is grateful for the research that has provided medications and treatments like DBS, which have improved her quality of life. She looks forward to the discovery of a cure for Parkinson's. For now, she is enjoying being a grandmother and just laughs when her son, who now has his own two-year-old boy, asks her how she did it all when they were young.



Cindy Smith shares a dance with her husband Tim.

DID YOU KNOW...

Each day in Canada, more than 10 people are diagnosed with Parkinson's disease.

Cognitive symptoms are common in Parkinson's; more than 60% experience memory limitations, anxiety and depression.

By 2031, the number of Canadians diagnosed with Parkinson's is expected to double.

For people with Parkinson's, time spent in residential care is up to 75 times higher than those without a neurological condition.

People with Parkinson's disease have the highest rate of prescription drug use compared to other neurological conditions.

Individuals with a neurological condition like Parkinson's may lose a total of 15 healthy years and die prematurely.

April is Parkinson Awareness Month

Parkinson's changes everything.
Learn more at parkinson.ca/DidYouKnow

Risk factors for Parkinson's

Researchers agree there are multiple risk factors associated with Parkinson's disease; environmental and occupational factors have been explored most recently. Research studies have identified a number of risk factors associated with Parkinson's including:

- ▶ Genetics (about 10 per cent of cases)
- ▶ Increasing age
- ▶ History of influenza
- ▶ Exposure to pesticides, insecticides, chemical solvents, and wood preservatives
- ▶ Increased levels of education
- ▶ History of head injury
- ▶ Exposure to high intensity body vibrations from heavy equipment
- ▶ Rural living and well water consumption
- ▶ Use of statins (cholesterol lowering drugs)
- ▶ Natural hair colour (lighter hair (blonde and red) particularly for younger onset of Parkinson's.)

Research also shows certain occupations associated with an increased risk of Parkinson's may include:

- ▶ Physicians
- ▶ Teachers
- ▶ Farmers and horticultural workers
- ▶ Legal professions
- ▶ Professional sports (hockey, football, boxing – in particular)
- ▶ Hairdressers
- ▶ Gas station jobs
- ▶ Aircraft mechanics
- ▶ Welders and heavy equipment operators
- ▶ Carpenters

For more information about Parkinson's disease and for help and hope for those living with Parkinson's, please visit www.parkinson.ca, email info@parkinson.ca or call 1-800-565-3000.

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